Injecting Drug Users and HIV/AIDS: Information Needs and Research Methods

Results of a Roundtable Session
at the
12th International Harm Reduction Conference in New Delhi
April 2001

Workshop was sponsored by:
FHI/IMPACT

Report prepared by:
Dr. Carol Jenkins

FHI implements the USAID IMPACT Project in partnership with the Institute of Tropical Medicine Management Sciences for Health ◆ Population Services International ◆ Program for Appropriate Technology in Health ◆ and the University of North Carolina at Chapel Hill.

This work was supported (in part) by the United States Agency for International Development (USAID) as part of Family Health International's (FHI) AIDS Control and Prevention (AIDSCAP) Project (623-0238-A-00-4031-00) and Implementing AIDS Prevention and Care (IMPACT) Project (Cooperative Agreement HRN-A-00-97-0017-00) and does not necessarily reflect the views of USAID or FHI

INJECTING DRUG USERS AND HIV/AIDS: INFORMATION NEEDS AND RESEARCH METHODS

Injecting drug use is one of the major factors in the increasing spread of HIV today in the Asian region, as well as the Middle East, South America, and in the CIS. There are many gaps in available information needed to guide a comprehensive response to the needs of IDUs, in general, and to the growing HIV epidemic among IDUs in particular. In response to the need for timely and comprehensive information related to the spread of HIV among IDUs, two important tools have emerged. These are the Rapid Situation Assessment (RSA) and the Behavioral Surveillance Survey (BSS). A session sponsored by the IMPACT Project of Family Health International held at the 12th International Harm Reduction Conference in New Delhi in March, 2001, reviewed these two methods. This paper will summarize the differences and similarities of these methods discussed at that meeting.

INFORMATION NEEDS

Many types of information can be used in response to the IDU situation in a given locale over time. Because a rapid response is the key to blunting an epidemic, moving quickly to gather basic information is imperative. The most important items may include those that are marked with a * below.

1. Drug related
    - types of drugs in use*, modes of use*, prices and shifts in prices, availability, modes of access, routes of trafficking, reported historical trends in drug types and modes of use

2. Geographical/demographic
    - where drug users are found and live*, urban/rural characteristics, population size, social-economic setting, drug use settings*
    - estimated size of drug using population by drug and mode of use*
    - social and economic characteristics of drug users*, i.e. age, gender, marital status, education, occupation, income, living

conditions, and people surrounding the user, e.g. dealers, injectionists
- special IDU populations, e.g. in prison, in the armed forces, HIV-infected IDUs

3. Legal and drug-related policy environment
- legal policies regarding different drugs and drug using paraphrenalia, enforcement levels, attitudes of law enforcement personnel*
- sentencing, drug use in prison
- extra-legal harassment of drug users, violence and criminality
- community attitudes and their involvement in shaping the policy environment*

4. Injecting equipment
- availability*, price*, quality
- legal/quasi-legal/illegal needle-syringe exchanges or other distribution systems*
- sharing behavior among IDUs (using other's used equipment or passive sharing, and giving used equipment to others or active sharing)*
- sharing of drugs, cotton wool, cooking or mixing equipment*

5. Sex related risk
- IDUs in the sex trade (male & female), distinguishing IDUs who sell sex to maintain drug habit from sex workers who also inject
- IDUs as clients of sex workers
- other non-marital/regular sex partners, gender of partners
- sexual practices*
- condom use*
- experience of sexually transmitted diseases (STDs), treatment-seeking behavior

6. Services for drug users
- drug abuse treatment facilities*, types, capacity, voluntary, mandatory
- HIV prevention programs*, types, location, coverage, effectiveness
- types of medical care available, attitudes of providers, abscess treatment accessibility
- expressed need for services by IDUs, other drug users

RAPID ASSESSMENT AND RESPONSE (RAR)

The methodology of rapid assessments, now called rapid assessment and response (RAR), is basically qualitative and descriptive, although some quantitative components may be included. The method was developed to be relatively quick and inexpensive so as to move all interested parties rapidly into undertaking the necessary response to the situation of HIV and drug use in any particular setting. Both primary and secondary sources, such as prior studies, clinic or law enforcement agency records can be used, but always require assessment for quality and triangulation with independent sources of the same information. Mapping, observations, focus group discussions or interviews with key informants (police, narcotics officers, health providers, local government officials, NGO personnel), IDUs themselves and other drug users, are also used.

The basic methodology can be supplemented, depending on available funds, time and expertise, with biological screening for HIV and other blood-borne viruses, more complicated methods of discerning the actual size of the IDU population, such as capture-recapture, and greater in-depth focus on specific issues, such as available treatment facilities. Mapping can be done simply or more elaborately, with observational annotation. Frequently, when the question of HIV prevention among IDUs arises in a nation, there are many commonly held ideas and opinions about IDUs among interested people that are not necessarily grounded in research findings. An RAR study helps to consolidate opinion in fact and move people towards the thoughts and actions needed to put prevention programs in place. In essence, a RAR study provides an opportunity to raise awareness about IDUs and their problems and for more evidence-based decision making.

Even after some programs are in place, additional RAR studies can fill other information gaps. If, for example, it were already known that IDUs were seriously at risk in one city and a program were already operating, an RAR conducted in selected areas in the rest of the nation would provide the necessary information for prioritizing which other areas needed interventions and in what order. In addition, the drug scene is a very dynamic one and monitoring its changing profile can also be done easily with selected components of RAR methodology.

The principal limiting design factor is that the method will not yield statistically sound quantitative data. Rapid assessments are most useful

prior to developing a response. They reach for a broad view of a local scene - its social, political, legal, and drug trade-related issues as well as specific pertinent information on IDUs themselves. These assessments are not designed to examine the interrelationships of factors contributing to the risk of acquiring an HIV infection or to evaluate the possible reduction in risk following interventions through statistical analysis.

BEHAVIOURAL SURVEILLANCE SURVEYS (BSS)

By contrast, BSS is basically a quantitative methodology with small ancillary qualitative studies considered optional. This method aims for statistical representativeness and is more suitable for tracking trends across time in behaviors and demographic or social factors that are associated with the risk of acquiring HIV among IDUs. Thorough mapping is a required component as sampling frames must be well described. Sample size must be calculated based on a key indicator, such as the proportion of IDUs who consistently do not share injecting equipment (either actively or passively) in a previous week or month. Questionnaire design requires pre-testing, and often written translations. As in all questionnaire surveys, there are few opportunities for open-ended questions and responses. If the most likely responses are not already known through a qualitative study, BSS is not a good method for exploring meaning or context in risk behaviors. Additional qualitative studies can be carried out following a BSS in order to aid in interpreting results, if necessary.

If implemented in a fully standardized manner across locales and time, BSS can be useful for comparing IDU populations within a nation or across nations, and within samples across time. Difficulties do arise, however, with highly mobile populations such as IDUs in establishing comparability and representativeness. Relatively simple and direct questions provide the best types of indicators for such comparisons. Detailed frequency data, such as the proportion of injections in the previous week that were intra-muscular vs. intra-venous, can be obtained, with confidence intervals and the ensuing capacity to examine change over time and inter-relationships among factors and outcomes. Levels of exposure and participation in prevention programs can be queried. Such data can be used for mathematical modeling and estimating the impact on HIV prevalence of needle exchanges or other interventions. Quantitative data require full computer management and analysis. Several months at least are needed to accomplish one round of BSS among IDUs.

METHODS COMPARED

Statistically, the BSS methodology is more rigorous than RAR, but in both cases, the validity and quality of the data and resulting reports depend on having experienced researchers in charge, sound selection and training of interviewers, and supervision in the field. Typically, training in sexuality and interviewing about sex are topics given lower priority in IDU studies, and may account for relatively superficial understanding of the full range of sexual attitudes and behaviors in different groups of drug users. Both methods require ethical procedures of consent or, in the case of using secondary data sources in the RAR method, permission for use. Both require and are greatly facilitated by the inclusion of IDUs themselves as researchers or guides. Both need adequate funding and at least 2-4 months of work, depending on the number of sites to be included. Most people feel RAR studies can be done more quickly, but that really depends on how elaborate they are and how experienced are the researchers. Both can be used for advocacy. The observational and in-depth interview components of RAR can provide a deeper understanding of context, but repeated, standardized BSS is the preferred method for evaluating the effectiveness of exposure to prevention programs. Because of the qualitative nature of the RAR method, it is more suitable when an initial study is needed to gain an overview in order to develop interventions. BSS can follow the introduction of an intervention to obtain sound baseline data. As prevention programs proceed, additional information gaps may remain; for example, in estimating how serious partner violence may be as an obstacle to utilization of services or to safe injecting, or in estimating the number of persons shifting from non-injecting drug use to injecting. Specific study designs would be required to fulfill these information needs and others. Manuals have been developed to aid researchers for both methods and are available in several languages.

In sum, these methods are complementary, accomplishing different tasks, and are best used together and at different times in a comprehensive program for reducing the risk of HIV infection among IDUs in any setting. Because of the illegal nature of injecting drug use almost everywhere, attitudes among decision-makers present serious obstacles to investment in prevention. Advocacy should be planned utilizing known alliances and addressing key decision-makers. The research findings should be clearly

and attractively presented. All the information that can be gathered and substantiated will be needed to advocate effectively.

SUMMARY

- **RAR** is designed to produce a broad view of the IDU situation in preparation for a quickly mounted response and preferred method to use before starting an intervention
- **RAR** is basically qualitative but can add biological and quantitative components as appropriate
- **BSS** is quantitative and utilizes small qualitative studies both in preparation and afterwards for purposes of improving interpretation
- **BSS** is the preferred method for measuring the extent of risk, tracking changes in behaviors and evaluating impact of interventions on behavior
- **BOTH** require skilled and trained personnel, ethical clearance and consent, varying amounts of time (depending on number of sites) and adequate funding
- **BOTH** can be used for advocacy and raising awareness of these critical issues
- **BOTH benefit by having IDUs directly involved**

REFERENCES

Meeting the Behavioural Data Collection Needs of National HIV/AIDS and STD Programmes. **IMPACT/FHI/UNAIDS:Bangkok,** May 1998.

Behavioral Surveillance Surveys: Guidelines for Repeated Behavioral Surveys in Populations at Risk of HIV. **FHI/IMPACT/USAID/DFID: Bangkok, 2000.**

The Rapid Assessment and Response guide on injecting drug use Eds. G.V. Stimson, C. Fitch and T. Rhodes, WHO/Substance Abuse Dept., 1998, Geneva.

For further information on rapid assessment studies on drug use visit:

www.RARarchives.org
www.who.int/substance_abuse/pubs_psychoactive_drugs.htm

Acknowledgements

This brief paper is based in part on presentations in a roundtable session entitled *Behavioural Surveillance Surveys and Rapid Assessments-Complementarities in Addressing Data Needs for HIV Epidemics among IDUs in Asia* held at the 12th International Conference on the Reduction of Drug-related Harm in New Delhi on April 4, 2001.

We would like to thank the participants in that session for their excellent presentations. Any errors, omissions or misinterpretations in this paper are solely the responsibility of the author.

The panel of speakers included the following persons:

Chair: Tobi Saidel (F.H.I.) & Tim Rhodes (U.K.)

Discussant: Peter Ghys (UNAIDS)

Tobi Saidel (Thailand)
BEHAVIOURAL SURVEILLANCE SURVEYS AND RAPID ASSESSMENTS - COMPLEMENTARIES IN ADDRESSING DATA NEEDS FOR HIV EPIDEMICS AMONG IDUS IN ASIA

Carol Jenkins (U.S.A.)
DOING BEHAVIOURAL SURVEILLANCE AMONG IDUS IN BANGLADESH

Don Des Jarlais (U.S.A.)
MULTIPLE METHODS FOR CONDUCTING RESEARCH ON HIV AMONG INJECTING DRUG USERS

Gerry Stimson (U.K.)
FUTURE DEVELOPMENT IN RAPID ASSESSMENT METHODS

Budi Utomo (Indonesia)
Behavioral Surveillance Survey among Injecting Drug Users in Jakarta 2000

Mukta Sharma (India)
RAPID SITUATION ASSESSMENTS: THE PROCESS AND OUTCOME-THE INDIAN EXPERIENCE

Summary by Carol Jenkins